

Founded in 1989

# The Post-Polio Support Group of Orange County NEWSletter

18552 Cork Street  
Fountain Valley CA 92708

## MARCH 2015

### MARCH MEETING

Travel Show

March 14, 2015

2:00 - 4:00 pm

Villa Park Council Chambers

We are happy to welcome back John Mowbray, Director of Orange County Travel Service. John has put together some wonderful travel trips for some of our PPS members over the years, such as the following:

1. Cruising the Mediterranean with ports in Spain, France, Italy and Greece
2. Sailing to Alaska via the Inland Passage
3. Touring/seeing the USA

John has a great ability to remove barriers to help make traveling much more relaxing and fun. Please join us with any of your travel questions. Let's keep enjoying our lives. Hope to see you there.

Submitted by Aleta Connolly

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### MAY MEETING

Dr. Susan Perlman

Sunday, May 17, 2015

2:00 - 4:00 PM

Villa Park Council Chambers

Join us for our annual "State of the Disease" and What's What in the World of Research on the Sunday following Mother's Day. Dr. Susan Perlman will be returning to bring us up to date on the latest in research and treatments for Post Polio survivors since last year.

We are extremely grateful for the information she shares each year on the trends and findings in the treatment and research on Post Polio. She is very much aware of the latest and most promising avenues currently being explored. Come hear where we are from the past years research to where we will most likely be going over the next.

### MY SINCEREST APOLOGIES TO OUR READERS

I wish to apologize for the lateness of this newsletter. I was ill for the past several weeks. First bronchitis, which turned to pneumonia and pleurisy and either a drug reaction or the stomach flu thrown in just to make me more miserable. Getting old can be a bit of a trial at times. Janet

## **GENERIC DRUG SAFETY WARNINGS**

The Generic Pharmaceutical Assn says a proposed federal regulation that would allow makers of generic drugs to inform people about all the known health risks would create “dangerous confusion” and have “harmful consequences for patients”. And why would that be?. For the answer, the industry group pointed David Lazarus toward a recent report from Matrix Global Advisors, an independent consulting firm. The report says the rule change would needlessly complicate the market and add \$4billion a year to already bloated healthcare costs. “Higher insurance premiums, self-insurance costs and reserve spending on product liability will likely force generic drug manufacturers to raise prices,” said Alix Brill, the head of Matrix and the report’s author. “Generic manufacturers also may exit or decline to enter the market for products with greater liability risk.”

It’s not until you reach the last page of the Matrix Report that you discover it was “sponsored” --- that is, paid for --- by the Generic Pharmaceutical Assn. David G. Savage, also of the Los Angeles Times, reported last year, generic drug makers are pulling out all the stops to fight the Food and Drug Administration’s attempt to provide consumers with more information about the possible risks of prescription drugs.

One would think any move to improve drug safety would be welcomed by all concerned especially in light of the fact that many pharmacies routinely substitute a generic drug in place of the one originally ordered by the doctor for cost savings purposes. As I have found over the years, I have to go to great lengths at times to make certain that I am given what my doctor has actually ordered. I have found to my cost, many generic drugs do not provide me with the required benefit as my body does not metabolize generics as it does the actual drug. It may be because of reformularization of the drug, too much filler or a host of issues, all of which are not supposed to happen, but in my body often do. One drug I take has at least a dozen generic varieties, only one of which actually works for me, and I cannot get any local pharmacy to order it for me so I must take the Brand name drug. It is a pain medication so, it’s inadequacies are immediately apparent the first day, or night, I begin using it. As this is only one of many such medications to which I react this way, I cannot believe I am alone in finding many generic drugs to be inadequate. My sister in law, who has no blood relationship to me, just one of marriage only, has similar responses to generics so her physician has stated unequivocally to her pharmacist that he is never to substitute her meds.

Indeed, one would think improved drug safety would be welcomed by all concerned. After all, no one wants a costly lawsuit related to misuse of a prescription drug or unwanted side effect. In this case, though, the \$240-billion US generic drug industry has long enjoyed different (read: looser) rules than those applied to brand-name drugs. And it likes things just as they are. “They will fight anything that could add to their costs,” said Mindy Marks, a health economist at UC Riverside. “That’s why we have an FDA --- to make sure consumers have enough information to make informed decisions about drugs”.

Makers of brand-name drugs have strict requirements about risk warnings. Just think about all those fast-talking voices at the end of commercials for everything from heart medications to pills that promise to make men more “manly”. The same doesn’t apply to generic drugs, and you can thank the five conservative justices on the Supreme Court for that. They decided in 2011 that generic drug companies don’t share the same level of responsibility as makers of brand-name equivalents to update their warning labels when a new risk comes to

light. The conservative justices followed this bizarre 5-4 decision again in 2013. They said that because generic makers are just following brand-name makers in their use of ingredients (or at least supposedly), patients can't sue them even if their product is found harmful.

In response, the FDA came up with a modest rule change that would help level the playing field. It would empower generic makers to update their warning labels any time new risks become known, rather than wait for federal authorities to require a change. More than 80% of prescriptions filled in the US are for generics, so we want to make sure that generic drug companies actively participate with the FDA to ensure that product safety information is accurate and up to date", said Janet Woodcock, director of the agency's Center for Drug Evaluation and Research. Seems reasonable enough, right? The FDA reasoned that if a company offers a drug to consumers, be it name-brand or generic version, it must stand behind the safety of that drug. Yet the generic drug industry says this would end the availability of relatively cheap alternatives and cause irreparable harm to the health care market. They want to let the FDA take the lead in determining notices of risks and changes. And we all know how quickly the FDA gets things done, right? That pretty much would let the Generic drug makers off the hook for the foreseeable future. That is pretty sad for consumers.

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## **DISCOUNT DRUG PLAN SUBSIDIES**

The pharmaceutical industry has been bragging for nearly the past ten years about its efforts to help patients pay for expensive prescription drugs. Big Pharma says these patient assistance programs are all about good works and helping patients.

"American's pharmaceutical and biotech

companies have been among the first in line to help struggling Americans" goes a typical industry pitch. "That's not government regulations at work, that's our sense of duty".

Well, no, actually, it isn't. "Assistance programs are a triple boon for drug makers." according to David Howard of Emory University in the New England Journal of Medicine. "They increase demand, allow companies to charge higher prices, and provide public relations benefits". These programs blunt efforts in Congress to rein in prescription prices by other means --- those that might actually bite into pharmaceutical profits.

The assistance program typically cover or put a cap on patient co-pays for prescribed drugs. Howard. Observes that these programs are especially useful for companies that market costly drugs, such as cancer drugs or those for rare diseases and conditions --- so called orphan drugs --- that may cost \$50,000 or more for a year of treatment. You may see or heard references to these discount programs flitting by at the end of TV commercials for prescription drugs.

High costs often discourage doctors from prescribing those drugs for patients, and discourage patients from following through on their doctors recommendations. "Patient-assistance programs can convert such patients from non-users to users", Howard writes. And while the discounts deals do impose costs on the companies, they get higher sales in return. "Manufacturers can afford to cover a lot of \$25 or \$50 co-pays in return for even a small increase in the \$50,000 drug." No kidding!!

Pfizer last year turned \$22 billion (that is with  
Continued on page 7

a B) profit on \$51.6 billion in revenue; Johnson and Johnson's profit was \$13.8 billion on \$71.3 billion in revenue; and Merck's profit was \$4.5 billion on \$44billion in revenue.

Patient assistance programs have drawn the scorn of healthcare experts and government monitors. They undermine such efforts to control prescription costs as steering patients towards generics or discouraging the use of costly new drugs that don't work any better than cheaper older drugs.

Insurers and government health programs use formularies to control drug costs --- charging higher co-pays for brand-name drugs or costly new versions --- but industry programs that cover those higher shared costs defeat their purpose. Federal health re regulators have warned that drug companies assistance programs that steer Medicare or Medicaid patients to their products by covering co-pays may run afoul of anti-kickback laws.

Further, once a patient becomes acclimated to a specific drug, his/her doctor might be very reluctant to change meds. Even if a newer drug is cheaper and as effective.

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This article in full may be viewed online at [LAT.ms/ImPJnTG](http://LAT.ms/ImPJnTG)

## **THE BACK NINE**

I FIRST STARTED READING THIS EMAIL & WAS READING FAST UNTIL I REACHED THE THIRD SENTENCE. I STOPPED AND STARTED OVER READING SLOWER AND THINKING ABOUT EVERY WORD. THIS EMAIL IS VERY THOUGHT PROVOKING. MAKES YOU STOP AND THINK. READ SLOWLY!

AND THEN IT IS WINTER

You know ... time has a way of moving quickly and catching you unaware of the passing years. It seems just yesterday that I was young, just married and embarking on my new life with my mate. Yet in a way, it seems like eons ago, and I wonder where all the years went. I know that I lived them all. I have glimpses of how it was back then and of all my hopes and dreams.

But, here it is... the back nine of my life and it catches me by surprise...How did I get here so fast? Where did the years go and where did my youth go?

I remember well seeing older people through the years and thinking that those older people were years away from me and that I was only on the first hole and the back nine was so far off that I could not fathom it or imagine fully what it would be like.

But, here it is...my friends are retired and getting gray...they move slower and I see an older

(THE BACK NINE (continued)

person now. Some are in better and some worse shape than me...but, I see the great change...Not like the ones that I remember who were young and vibrant...but, like me, their age is beginning to show and we are now those older folks that we used to see and never thought we'd become.

Each day now, I find that just getting a shower is a real target for the day! And taking a nap is not a treat anymore... it's mandatory! Cause if I don't on my own free will... I just fall asleep where I sit!

And so...now I enter into this new season of my life unprepared for all the aches and pains and the loss of strength and ability to go and do things that I wish I had done but never did!! But, at least I know, that though I'm on the back nine, and I'm not sure how long it will last...this I know, that when it's over on this earth...it's over. A new adventure will begin! Yes, I have regrets. There are things I wish I hadn't done...things I should have done, but indeed, there are many things I'm happy to have done. It's all in a lifetime.

So, if you're not on the back nine yet...let me remind you, that it will be here faster than you think. So, whatever you would like to accomplish in your life please do it quickly! Don't put things off too long!! Life goes by quickly. So, do what you can today, as you can never be sure whether you're on the back nine or not!

You have no promise that you will see all the seasons of your life...so, live for today and say all the things that you want your loved ones to remember...and hope that they appreciate and love you for all the things that you have done for them in all the years past!!

"Life" is a gift to you. The way you live your life is your gift to those who come after. Make it a fantastic one. LIVE IT WELL! ENJOY TODAY! DO SOMETHING FUN! BE HAPPY ! HAVE A GREAT DAY Remember "It is health that is real wealth and not pieces of gold and silver. LIVE HAPPY IN 2015!

LASTLY, CONSIDER THIS:

~Your kids are becoming you.....but your grandchildren are perfect!

~Going out is good.. Coming home is better!

~You forget names.... But it's OK because some people forgot they even knew you!!!

~You realize you're never going to be really good at anything like golf.

~The things you used to care to do, you aren't as interested in anymore, but you really do care that you aren't as interested.

~You sleep better on a lounge chair with the TV 'ON' than in bed. It's called "pre-sleep".

~You miss the days when everything worked with just an "ON" and "OFF" switch..

~You tend to use more 4 letter words ... "what?"..."when?"... ???

~You notice everything they sell in stores is "sleeveless"?!!!

~What used to be freckles are now liver spots.

~Everybody whispers.

~You have 3 sizes of clothes in your closet.... 2 of which you will never wear.

~~~But Old is good in some things: Old Songs, Old movies, and best of all,OLD

THE BACK NINE (continued)

FRIENDS!!

Stay well, "OLD FRIEND!" Send this on to other "Old Friends!" and let them laugh in AGREEMENT!!! It's Not What You Gather, But What You Scatter That Tells What Kind Of Life You Have Lived.

TODAY IS THE OLDEST YOU'VE EVER BEEN; YET THE YOUNGEST YOU'LL EVER BE, SO ENJOY THIS DAY WHILE IT LASTS.

“Do Not Regret Growing Older. It is a privilege Denied to Many. “

Submitted by Debbie Hardy

**THANK YOU!!!!!!**

I would like to extend a very heartfelt THANK YOU to both Aleta Connolly and Debbie Hardy. Without their contributions to this month's newsletter it may well not have gotten out.

Very much appreciated. ladies. Janet

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LY LEFT BLANK



## Rancho Los Amigos Meeting

*Future Rancho SG Meetings*

*PPSG of OC Meetings*

**SATURDAY,  
MARCH 14, 2015  
2-4PM  
TRAVEL SHOW**

**SUNDAY,  
MAY 17, 2015  
2-4 PM  
Villa Park City Council  
Chambers**

### **How to contact Rancho Support Group**

The Rancho Los Amigos Post-Polio Newsletter is published as a joint venture with the Polio Survivors Association.

For additional information please call Richard at **562-862-4508**

Or email us:  
**Rancho PPSG@hotmail.com**

### **How to contact OC Support Group:**

Call us for information:

Marilyn Andrews **714-839-3121**

#### **Newsletter Editor**

*Janet Renison* 949-951-8613

[renison@lagunawoodsvillage.net](mailto:renison@lagunawoodsvillage.net)

#### **Agenda ideas for PPSG of OC?**

Please call Aleta at 949-559-7102 or email

Priscilla at [prisofoc@aol.com](mailto:prisofoc@aol.com)

Special thanks to our donors. We mention donations but not the amount, as all donations make our support group possible. Please write checks to **Polio Survivors Association** and write "Orange County" in the memo section. Please **mail checks to** Priscilla Hiers, Treasurer PPSG of OC, 18552 Cork Street, Fountain Valley, CA, 92708.

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**Orange County Post Polio Support Group**  
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**Fountain Valley, CA 92708**

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 THE BLIND AND  
 PHYSICALLY DISABLED**

**RETURN SERVICE REQUESTED**

